

# Highlights: Annual Report

Maryland Developmental Disabilities Council

## A Message from THE MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

Dear Friends and Colleagues,

Welcome to the Maryland Developmental Disabilities Council's 2010 annual report. The Council was established as an independent systems change agent through federal law over 40 years ago and we remain 100% federally funded.

While Highlights provides an overview of the past year, it is also important that we focus on the future. Much of what we did in 2010 serves as the foundation for our ongoing advocacy, capacity building and systems change activities in Maryland. In this report, we highlight the key public policy work we engaged in, initiatives the Council invested in, successful sustainability efforts and next steps. We encourage you to follow the links provided to learn more, to get involved, to replicate successful initiatives, or to receive copies of publications and other materials you can put to use.

During the course of 2010, we were successful in moving some issues forward in leaps and bounds, while others remain entrenched. The Council will learn from our work in 2010 and change course as necessary and work to replicate promising and proven practices. We will continue to empower people with disabilities to be in control of their own lives and leaders in the movement to ensure our communities welcome, support and fully include all people with developmental disabilities.

There are far more barriers to full inclusion for people with developmental disabilities than the Council can meaningfully and successfully address. As with any organization, this requires strategic planning and priority-setting. For the Council this takes the form of a Five-Year State Plan, which serves as the roadmap for effectively utilizing the Council's human and fiscal resources to impact our priorities in significant, expansive and lasting ways. After much research and analysis, stakeholder input and discussion, the Council will soon finalize our new plan, which will take effect October 2011.

We welcome your partnership to continue moving Maryland forward.

Sincerely,

Chairperson

Brian Cox

**Executive Director** 

## **OUR VISION**

The Council believes that all people with developmental disabilities should receive the support they need to maximize independence, be productive, and lead the lives they choose in the community. Practices that segregate and isolate people with disabilities must end.

## **OUR MISSION**

The Maryland Developmental Disabilities Council is a public policy organization that advocates for the inclusion of people with developmental disabilities in all facets of community life.

## TO ACCOMPLISH OUR MISSION THE COUNCIL:

- Educates and informs policymakers about issues of importance to people with developmental disabilities and their families.
- Advocates for services, policies and practices that support people with developmental disabilities to exercise self-determination and lead productive, fulfilling lives.
- Designs and funds innovative projects that promote community inclusion and improve services and supports.
- Focuses on bringing about lasting improvements in the areas of: education and early intervention, child care, employment, transportation, community supports, recreation, housing, health, and quality assurance.

The majority of Council Members are people with developmental disabilities or family members of people with developmental disabilities. One member is a person or a family member of a person once or now institutionalized. The Council includes representatives from state agencies, the Protection & Advocacy System (Maryland Disability Law Center) and the University Center on Excellence in Developmental Disabilities (Maryland Center for Developmental Disabilities). Other Council members include representatives from local agencies and non-profit organizations that provide services and supports to people with developmental disabilities.

## IMPLEMENTING DIVERSE STRATEGIES TO SUPPORT INSTITUTIONAL CLOSURE

"The news that
Rosewood would
close was
devastating. But it
ended up being one
of the best things
that ever happened
to Roslyn, and to us."
—Ida, Roslyn's sister

## EDUCATING POLICYMAKERS & THE PUBLIC

The Council set out to capture the changes that occur in people's lives when they transition out of institutions to live their lives in the community. This took the form of a short documentary called *Departing Rosewood* and a publication aptly named *What's Possible*.

The production of the documentary was spearheaded by the Council and co-funded with the Maryland Department of Disabilities and Developmental Disabilities Administration. An Academy award winning filmmaker from Maryland was selected to produce the film, which premiered on Maryland Public Television and was viewed by over 6000 households.



What's Possible: Nine Stories of Changed Lives was produced to help families, policymakers and the general public better understand what is possible when people with significant disabilities are given new opportunities and the community supports they need. Told from the perspective of the nine people and their families, it has been distributed widely throughout the state. Organizations in Maryland and 11 states have requested multiple copies to use in their educational efforts.



Free copies of *Departing Rosewood* are available for educational and training purposes. Contact the Council at 1-800-305-6441 ext. 1 or *info@md-council.org* for a copy of the DVD and for copies of *What's Possible* or download the publication at *www.md-council.org*.

"I promise, you will be astonished at how much it will make you care about the young man at the center of the film... catch it if you can."

– David Zurawik, Baltimore Sun TV Critic. Review of Departing Rosewood

## **BUILDING CAPACITY**

The Council served as an active member of Developmental Disabilities Administration's (DDA) Community Expansion Workgroup to develop a more comprehensive, effective community service system for people with developmental disabilities involved in the criminal justice system. In support of the workgroup's charge, the Council committed up to \$15,000 to bring national experts to Maryland to provide technical assistance. We worked with DDA, judges, providers, advocates and other stakeholders to identify and coordinate the delivery of the technical assistance and to develop recommendations.

## ADVOCATING FOR BEST PRACTICES

Maryland has plans to develop a 60-bed facility for people with developmental disabilities involved in the criminal justice system. The Council and many other advocates oppose a facility-based approach, especially one of this magnitude. Instead the Council continued to advocate for community-based services, which have been proven effective in other states.

## ADVOCATING FOR ESSENTIAL COMMUNITY SUPPORTS

## ADVOCATING SOLUTIONS - TEN CENTS MAKES SENSE

In 2010, the Council and the DD Coalition joined forces with mental health, addictions and healthcare advocates to support the Lorraine Sheehan Health & Community Services Act. Through a dime a drink increase to the state alcohol tax, this Act would have raised over \$200 million annually for these community needs, including the DDA Waiting List and underfunding of existing community services for people with developmental disabilities. Although the legislation didn't pass, education of the Governor, legislators and the public intensified and support for funding these causes increased significantly, providing a solid foundation for next session.

# 10 ¢ents Makes Sense

## SUPPORTING THE GRASSROOTS

Through a grant from the Council, The Arc of Maryland coordinated and expanded the End the Wait Now! Campaign (ETWN), a grassroots movement that aims to make the DDA Waiting List a Maryland public policy and funding priority. In FY2010, the ETWN Campaign:

- In partnership with the Developmental Disabilities Coalition, sponsored nine Town Hall meetings about the Waiting List crisis and underfunding of community services. Over 2700 people attended and the press covered these events, including CNN;
- O Distributed 15 Waiting List stories to over 2200 people, including elected officials and the media;
- Testified at budget and bill hearings;
- Led the grassroots response to action alerts; and
- Worked with Loyola College's "Art of the Argument" class, whose students acted on behalf of the campaign by developing Waiting List stories, writing the governor and legislators, and utilizing social networking media to communicate the Waiting List message to their peers.

In conjunction with these efforts, the Council also:

- Maintained the www.EndTheWaitNow.com website, which was expanded in 2010 to serve as a one-stop information center for families, advocates and the media.
- Utilized a media consultant to obtain consistent media coverage of developmental disability policy and funding priorities. Over 50 newspaper reports included coverage.

## SUPPORTING INNOVATIVE HOUSING STRATEGIES & PARTNERSHIPS

Expanding housing options that are affordable to people with developmental disabilities remains a complex challenge. With housing costs rising over the past decade and SSI benefits and income not keeping pace, the Council stopped focusing on homeownership because of the limited impact and instead widened our strategies around affordable rental. In 2010, the Council and the Maryland Department of Disabilities initiated an innovative

partnership between the Department of Housing and Community Development (DHCD) and the Weinberg Foundation, one of the largest private foundations in Maryland. Planning began in 2010 around how to utilize private and public funds to increase the number of rental units that are affordable to people with disabilities and very low incomes. The partnership resulted in \$1 million committed by the Weinberg Foundation for 2011-2012.

## DEVELOPMENTAL DISABILITIES DAY AT THE LEGISLATURE

Even with the threat of snow, nearly 350 people participated in Developmental Disabilities Day at the Legislature in 2010. People with disabilities, family members, service providers, and advocates were joined by legislators to advocate for priority legislation and budgets. Participants were heard loud and clear by legislators and the press as they marched and chanted "10 Cents Makes Sense!" in support of the Lorraine Sheehan Health & Community Services Act. Following the march, meetings were held with senators and delegates and education/advocacy materials were delivered to all legislators.





## ADVOCATING FOR PUBLIC POLICY PRIORITIES

In partnership with our DD Coalition partners, the Council:

- Utilized a range of education & advocacy strategies to minimize cuts to developmental disability community services and gain support for additional community funding;
- Supported efforts to gain updated, accurate information about everyone on the DDA Waiting List and advocated for more accountability and revised processes to ensure the outcomes were fair and accurate;
- Broadened legislative support for the DDA Waiting List. More legislators committed to finding a solution and the Women's Legislative Caucus made this one of their top 2010 priorities;
- Promoted policy and programmatic reforms to improve the Low Intensity Support Services program. Legislation passed that protects critical components of LISS; and
- Reviewed, analyzed and advocated on regulations, policies and other actions pertaining to access to services, resource coordination, Medicaid waivers, and service provision.

## **NEW MARYLAND INCOME TAX CHECK-OFF**

In 2010, legislation passed that provides an opportunity for Marylanders to contribute a portion of their tax return to fund community supports and services for people with developmental disabilities. To help spread the word and gain support, the Council committed funds for the design and printing of public awareness materials. For more information: www.endthewaitnow.com



## ADVOCATING FOR INCLUSIVE CHILD CARE - CLOSING THE SCHOOL READINESS GAP

Maryland data shows that where a child receives early care and education influences his or her preparedness for school. Children who receive child care in a more formal

setting such as a child care center or nursery school enter kindergarten more ready to learn than those in informal care. Yet, many of these settings still remain inaccessible to children with disabilities and their families. Young children with disabilities have the lowest rate of school readiness compared to any other group.

To address this, the Council continued collaborating with Maryland State Department of Education's (MSDE)

Division of Early Childhood Development to promote inclusive, high quality and accessible early childhood so that young children with disabilities can learn and play with their typically developing peers. This included development of a quality rating and improvement system.

We successfully advocated for quality measures that impact children with disabilities, including required training so child care providers learn more inclusive

practices. The new quality rating and improvement system will be piloted this summer.

The Council also worked with the Office of Child Care and other stakeholders to modify the credentialing requirements for child care providers. As a result, providers who choose to participate in the credentialing program will have to take more training, including a specific training on the inclusion of children with

disabilities in child care and after school care. These changes to policy and practices, coupled with increased coordination and collaboration, will help more children with disabilities and special health care needs have access to inclusive child care settings and programs.



## **CONTINUATION UPDATE**

## THE COMMUNITY WORKS PROJECT

Maggie's Light Foundation originally received Council funding in 2009 to increase respite care options for families of children with developmental disabilities. The project, a partnership between the Maggie's Light Foundation, Towson University's Occupational Therapy Program, and The Arc of Baltimore Family Support Services, matched students studying in disability related fields with families looking for respite caregivers. The Foundation received a grant from the Maryland Community of Care Consortium for Children with Special Health Care Needs to continue and expand project activities. www.maggieslight.org

## **FAMILY NETWORKS**

The Council's Family NetWorks website averaged nearly 8000 visitors each month in 2010. The site spotlights current issues and promising practices, includes extensive links to resources across the lifespan and connects families with information and training. The website is undergoing a face lift, to be unveiled in 2011, to make it a more effective and user-friendly resource. A related list serve links over 280 parents and advocates for information and resource sharing. www.family-networks.org





The Council addressed the low rate of inclusion of students with developmental disabilities in neighborhood schools by working in collaboration with other disability organizations and state agencies to educate parents and providers and influence state and local education policies. In 2010, our leadership on this issue also included bringing together key stakeholders to begin exploring ways to work with higher education to more effectively prepare general education teachers to teach students with disabilities in general education classrooms. In 2011, the Council will facilitate additional strategy development between stakeholders and select institutes of higher education.



## The Council also:

- Testified before the legislature about the education budget as it impacts students with disabilities, the need for universal design for learning, and why parents of students with disabilities must be meaningful participants at school meetings. Our goal is to build capacity in the local school systems so students with disabilities are educated in the least restrictive environment.
- Served as chair of the Special Education State Advisory Committee and worked to establish priorities and goals that will better assist the Division of Special Education/Early Intervention Services in improving the delivery of special education and related services to all children with disabilities and their families.
- Partnered in a statewide annual Poster & Essay contest in elementary schools celebrating National Inclusive Schools Week to educate and engage students and teachers about inclusion.

## LEADERSHIP ACTION NETWORK AND ACTION GROUPS

Through a grant from the Council, the Maryland Coalition for Inclusive Education developed and implemented a refined and enhanced approach to training and supporting parents and young adults with disabilities to be effective and active education advocates and leaders. The focus was on improving local policies and practices so more students with developmental disabilities are educated in neighborhood schools alongside their non-disabled peers.

In 2010, MCIE trained 16 parent leaders and 2 students with disabilities and developed action groups in 4 counties to sustain advocacy. Throughout the year, leaders met with local school system administration, school board members, County Council members, and local parent groups to discuss inclusive practices. After the Council's funding ended, MCIE was successful in acquiring other sources of funding to continue this work in 2011. www.mcie.org

## **CONTINUATION UPDATE**

## HOMES (HELPING TO OBTAIN MEDICAID ESSENTIAL SERVICES) PROJECT

With Council funding the MD Disability Law Center's project had significant accomplishments impacting 4 systems change issues: 1) creation of a single statewide DDA process for Medicaid waiver participants to request needed services; 2) improvement in a process that prevents or shortens nursing facility stays for people with developmental disabilities; 3) establishment of a process for REM participants to maintain in-home nursing and home health aide services after they turn 21; and 4) creation of a consistent process for local health departments so that people denied services under the Medical Assistance Personal Care program receive written responses explaining the reason for denial and the right to request a fair hearing. The project impact extends to the 10,000 Maryland Medicaid Waiver enrollees with developmental disabilities. MDLC will continue to support the project through the organization's fundraising efforts.

## MAKING A SUSTAINABLE IMPACT THROUGH HEALTH CARE INITIATIVES

## **FAMILIES AS FACULTY**

2010 marked the final year of Families as Faculty, a project of The Parents' Place of Maryland. The project offered pediatric residents, medical students, and masters-level health professionals a home-based training experience to learn from families what it's like to raise children with developmental disabilities. Over the life of the project, 87 families hosted 187 students. Students' remarks demonstrated the value of their experiences. One student reflected "Raising a special needs child affects the entire family dynamic and recognizing that this is not an isolated patient with an isolated condition is important. The health of the special needs child depends on that family's abilities to cope and create normalcy in their lives which must be encouraged by the physician."

## IMPACT OF CONSENT

Resource Connections of Prince George's County completed the Impact of Consent project through Council funding to promote quality healthcare for people with disabilities, through education of family members, service providers, healthcare providers, and the individuals themselves, about issues of decision-making and true informed consent. The project developed a website for several audiences and trained 227 self-advocates, families, provider and nursing staff. <a href="http://myhealthconsent.org">http://myhealthconsent.org</a>

## BUILDING STAFF SKILLS AND ORGANIZATIONAL CAPACITY TO OFFER CUSTOMIZED EMPLOYMENT SERVICES

The Council, in partnership with DDA and the Maryland Department of Disabilities, awarded grants to five organizations to improve employment outcomes of people

with developmental disabilities. The grants are assisting providers to make organizational changes and build staff skills so that they can offer customized employment services and supports. The five providers are: Friends Aware, Community Support Services, The League, Family Services Foundation, and UCP of Southern Maryland (in partnership with The Center for Life

Enrichment and Abilities Network, and St. Mary's County Government, Department of Human Services).

The providers receive targeted training and technical assistance in order to implement a range of activities. Training topics include person-centered planning, customized employment, and development of community connections, while technical assistance assists with strategic planning, organization redesign, and networking facilitation. As a result of these grants and a small grant to Penn-Mar Human Services, 47 people with developmental disabilities are successfully employed in the community.

Concurrently, the Council awarded a grant to TransCen, Inc. to facilitate the development of a peer network that focuses on supporting agencies as they build systems and

organizational capacity to offer customized employment services and supports. The Maryland Organizational Change Peer Network provides opportunities to share

information, learn from each other, discuss topics of interest to the group, and identify systems issues.

In addition to the six participating agencies, the Developmental Disabilities Administration and Division of Rehabilitation Services are active partners in the Network. The benefits of this initiative will extend beyond the

Network participants; TransCen will compile a report about the work of the Network that will be disseminated to others interested in organizational change.

The Council is also active in employment at a state level. The DDA developed an "Employment First" policy so that more people with developmental disabilities are successfully employed in the community in jobs of their choice. The initiative is guided by an Employment First Advisory Group that recommends policies and strategies for implementation. The Council serves on the advisory group, as well as an Infrastructure Workgroup. The Workgroup drafted definitions for regulations and continues to work on outcome measures.





## STRENGTHENING AND EXPANDING SELF-ADVOCACY

## PEOPLE ON THE GO OF MARYLAND: SELF-ADVOCACY ON THE MOVE

In 2010, the Council expanded on our long history of supporting self-advocacy to incorporate new strategies and priorities. The Council invested in People On the Go of Maryland (POG), the statewide advocacy group led by people with developmental disabilities, to focus on invigorating the self-advocacy movement and expanding to under-represented areas of the state. POG set out to enhance the group's autonomy and decision-making process, better support local groups, and increase their influence on key public policy issues.

POG identified other local self-advocacy groups that existed but were unaffiliated, which have now been added to their consortium. In addition, to address a goal shared by the Council and POG, the Council provided funds to expand activities to the Eastern Shore, a typically underserved area of the state with regard to self advocacy. Initial steps were



taken to establish and support three new self-advocacy groups in that area, thereby expanding the statewide self-advocacy consortium. Through these expanded activities, POG will support the development of the new groups and coordinate their activities with the statewide self-advocacy movement.

The Council's investment will support active, effective and sustained statewide self-advocacy that is focused on key developmental disability issues.

## LEARN ABOUT THE STATE LEGISLATIVE PROCESS AND IMPACT IMPORTANT ISSUES

The Council will sponsor another legislative internship in 2012!

Contact People On the Go of Maryland for details or to apply. ken@poqmd.org

## OTHER INITIATIVES

## HER ASSOCIATES, EQUAL ACCESS TO INFORMATION AND RESOURCES RESEARCH PROJECT

In 2010 the Council selected Health and Education Research Associates (HER) to research if people with developmental disabilities and their families from the Hispanic community have equal access to information and resources from specific disability service systems as other people with developmental disabilities and their families. HER's report suggests recommendations in the areas of improved data collection, service delivery, early education, and transition services. The Council will implement specific recommendations through Council projects, systems change, and advocacy work in 2011 and beyond.



The Council's Small Grants are utilized in many different ways to educate and train people with developmental disabilities and their families, support communities, and increase advocacy efforts. Below is a diverse list of activities in 2010:

- People On the Go of Prince George's County: created, printed, and distributed brochures that resulted in the recruitment of 23 new members and attended training on how to be an effective advocate.
- MD Respite Care Coalition Annual Conference: doubling its attendance from last year, over 450 participants learned crucial information regarding funding opportunities, respite services, and community programs. 60 informative workshops were offered.

- Diamond Dreams: inclusive fitness & athletic program offers team sports for youth with and without disabilities and a unique mentoring program involving volunteers from the community.
- MD Department of Disabilities: The Council supported the 20th Anniversary celebration of the signing of the Americans with Disabilities Act attended by the Governor and over 200 people with disabilities, families, and professionals.
- The Arc of the Northern Chesapeake Region: The Relationships, Sexuality and Values that are Personalized training provided information for people with developmental disabilities, family members and professional support staff regarding different types of relationships, dating and marriage, as well as how to guard against abuse.
- Howard County Autism Society: Advocacy in Action Creating Positive Change presentations provided training for 95 people with developmental disabilities, family members, educators, and state and local public sector employees on advocacy skills and effective communication.



Governor O'Malley and Damon Briggs, ADA Anniversary 20th Event.

## **NEW PROJECTS FUNDED BY THE COUNCIL IN 2011**

## EXPANDING THE USE OF ASSISTIVE TECHNOLOGY

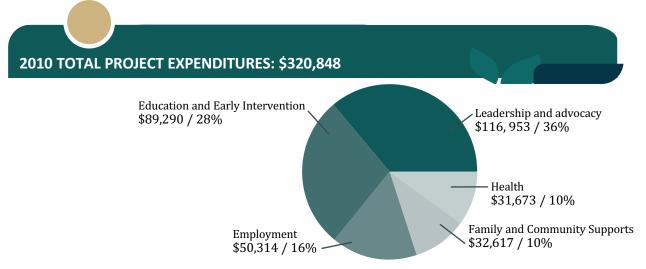
All Together in the Mountains, a project of AT: LAST, will promote awareness of assistive technology in Garrett and Allegany Counties through education of childcare providers, service providers and other key organizations resulting in increased access to assistive technology for people with developmental disabilities. The project will also expand the expertise of educators, related service personnel, and service coordinators by building professional development courses at colleges. Finally, a Picture Symbol version of the Individual Service Plan will be created so that people with developmental disabilities can better communicate their wishes and self-direct their plans. www.matcoop.org

## PROVIDING INNOVATIVE OPTIONS FOR LEARNING

Maryland Family Network, a statewide organization that works to improve the availability and quality of child care, family support services, and early education, will develop and implement an innovative web-based learning module about children with developmental disabilities in child care settings and specific strategies to ensure inclusion. The result next year and beyond will improve the knowledge and skill base of child care providers so more children have access to quality, inclusive child care. www.marylandfamilynetwork.org

## REACHING THE HISPANIC COMMUNITY

The Hispanic Outreach Project, an initiative of The Arc of Maryland, will improve access to services and resources for members of the Hispanic community who have developmental disabilities and their families. By providing information, resources, and training to local chapters on how to conduct outreach to the Hispanic community, providers will have strategies to reach people with developmental disabilities and their families to offer supports and services.



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